

Foundations to building effective partnerships

Patient and Public Involvement: Building Partnerships Across the VCCC

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What is public involvement in research?

The National Health and Medical Research Council defines involvement as:

“research being carried out **with or by** consumers and community members rather than to, about or for them.”



Australian Government

National Health and Medical Research Council

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Why public involvement in research?

The National Health and Medical Research Council states:

“Active **involvement** of consumers and community members in health and medical research **benefits the quality and direction of research**”



Australian Government

National Health and Medical Research Council

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Why involve the public?

The **Australian Commission on Safety and Quality in Health Care** states that:

‘patients and carers, in partnership with health service organisations and their healthcare providers’ should be involved in:

- making decisions for service planning
- developing models of care
- measuring service and evaluating systems of care

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

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Why involve the public?

“when patients or patient representatives are involved in projects in a meaningful way, the results can contribute more effectively towards patient-centred, **equitable healthcare**”

The Value+ Toolkit, For Patient Organisations On Meaningful Patient Involvement, European Patients' Forum



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The future is already here — it's
just not very evenly distributed.

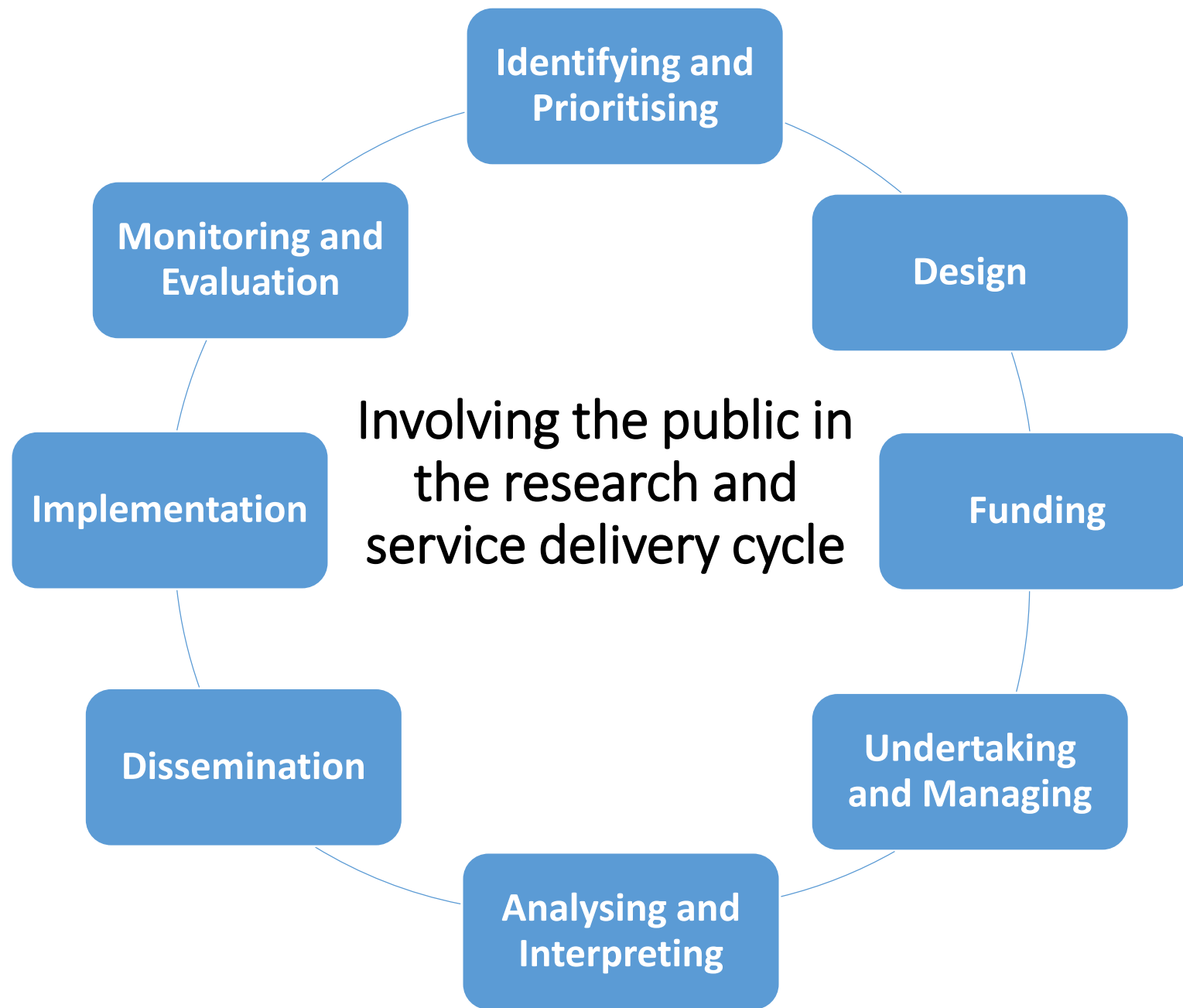
William Gibson

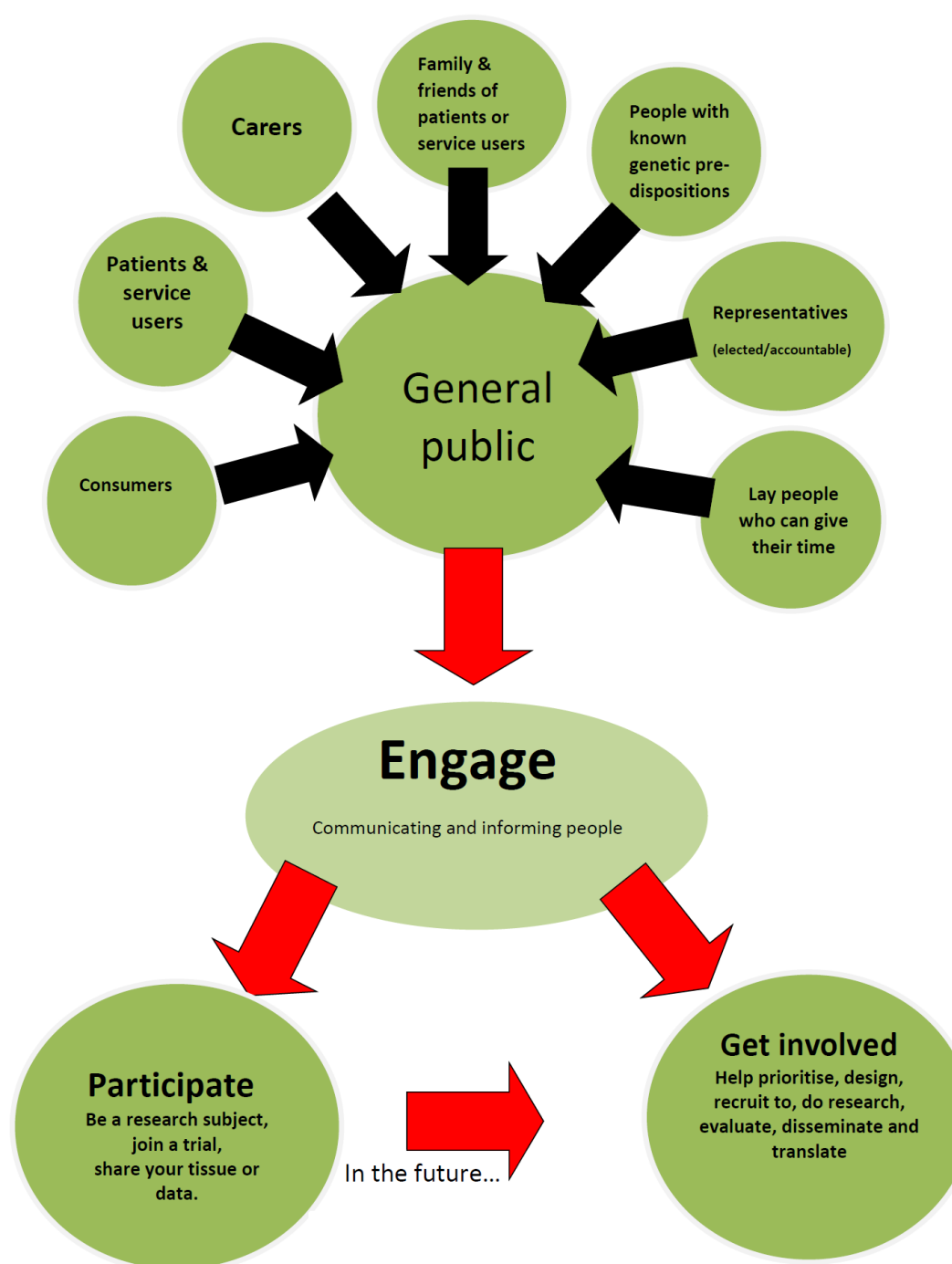


Australian Government

Cancer Australia

- Requires evidence of consumer involvement in all grant applications
- Created a 'National Framework for Consumer Involvement' states we must 'place the needs of people the need to of people most affected at the centre of all policy planning, service delivery, research, information and support'





Examples of involvement



**BUILDING
RESEARCH
PARTNERSHIPS**

macmillan.org.uk/researchlearning

BUILDING RESEARCH PARTNERSHIPS

WE ARE
MACMILLAN.
CANCER SUPPORT

Research is for everyone.
Everyone can help shape the future of research.

By sharing free resources and working in partnership across health conditions, we can help a greater number of people get involved in shaping the future of health and social research.

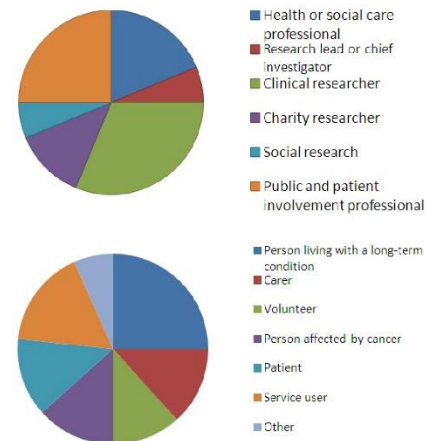
What have we done?

Over the last three years we have trained 10 facilitators to run over 30 events across the UK to support public involvement in research for over 700 researchers and members of the public.

How did we do it?

Macmillan Cancer Support developed a number of three-year partnerships at a national level in three different countries by sharing our resources with national organisations with a remit for public involvement in research. We helped them take ownership by encouraging them to budget for the training of local lay-facilitators and committing to pay them to run a programme of **shared learning events for members of the public and professionals** about public involvement in research. Our partners include the *Public Health Agency (Northern Ireland)*, the *National Institute for Social Care and Health Research Clinical Research Centre (Wales)* and the *National Institute for Health Research (England)*.

Who attended the events?



Results

98% of participants thought that public involvement in research had made a difference or had an impact.

96% of professionals said as a result of attending, their understanding of how to involve the public in research has increased.

75% of the public who attended said their involvement in research has increased since attending the course.

72% of professionals said they involved the public more in their research since attending.

Conclusion

Building Research Partnerships has demonstrated a **successful model of working** for helping the public improve and shape the future of research across health conditions. It has made a **measurable impact** on practice and has received **international recognition**.

Macmillan.org.uk/researchlearning

Email: research.learning@macmillan.org.uk or contact Jack Nunn on Twitter @jacknunn



“If patient engagement were a drug, it would be the blockbuster drug of the century and **malpractice not to use it.**”

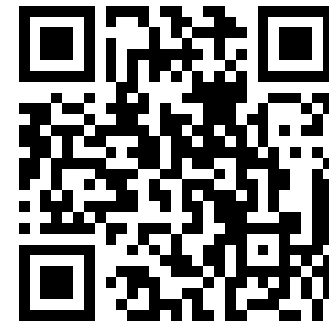
RESEARCH INVOLVEMENT
AND ENGAGEMENT

What can you do now?

- Talk to people
- Find support
- What do you want to do?
- Make a plan
- **Collaborate!**
- What resources or support do you need?
- **Do something, start early**
- Evaluate it, measure the impact

Resources and contact

- Email: Jack.Nunn@Latrobe.edu.au or Jack.Nunn@gmail.com
- Join LinkedIn group '[Public and consumer involvement in health and social research – Australia](#)'
- Download handout at www.Twitter.com/jacknunn or search @jacknunn



Share and share alike

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Some of the resources in this manual have been adapted from:

‘Building Research Partnerships’, created by Macmillan Cancer Support and available under the same licence.

More information about that resource can be found here: macmillan.org.uk/researchlearning

Acknowledgements

This resource was created by Jack Nunn for the Victorian Comprehensive Cancer Centre (VCCC), 2016. Please send any feedback to Jack.Nunn@gmail.com – or via Twitter [@JackNunn](https://twitter.com/JackNunn)